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Visual Hallucinations in Dementia and Parkinson's Disease: A Qualitative Exploration of Patient and Caregiver Experiences

Key words: Visual Hallucinations, Dementia, Parkinson's Disease, Qualitative Methods

Key points:

- This study employed qualitative methods to explore the visual hallucination experience from the perspective of individuals with dementia, Parkinson's disease, and their informal caregivers.
- Differences in the VH experience between persons with dementia and PD were less striking than the overall similarities across conditions at equivalent stages of cognitive and insight impairment.
- Insight influenced the perceived threat of visual hallucinations and whether acceptance occurred over time. Those with more advanced cognitive impairment were more likely to experience VH as frightening unless appropriate reassurance was received. Concerns around stigmatisation were common in participants with Parkinson's, and inhibited disclosure and acceptance of the hallucinations. Carers' responses were adapted and their distress increased as participants' insight and cognition declined.
- Irrespective of the clinical context, tailored support is required that takes into account the degree of insight and cognitive function. When preserved, the focus should be on raising awareness of VHs, symptom disclosure, stigma reduction, and contact with others affected. When impaired, the focus shifts to informal caregiver needs and a flexible approach to re-assuring those affected.

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Conflict of Interest

None of the authors have a conflict of interest to declare.

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Abstract

Objectives

Visual hallucinations can occur in several clinical conditions, of which the dementias, broadly defined, and Parkinson's disease rank amongst the most common. There is limited research on the lived experience of hallucinations among affected individuals and therefore a lack of evidence-based management strategies. This study employed qualitative methods to explore the visual hallucination experience of individuals with dementia or Parkinson's disease and their informal caregivers.

Methods

In-depth interviews were conducted with 10 individuals with visual hallucinations and dementia and 11 informal caregivers, and 11 individuals with visual hallucinations and Parkinson's disease and 9 informal caregivers. Interviews were analysed using an inductive thematic approach.

Results

Three themes emerged from the data: 'Insight and distress', 'Caregiver approach: challenging v reassurance' and 'Normality and stigma'. Insight appeared to affect whether hallucinations were perceived as threatening and whether acceptance occurred over time. Emotional reactions and management strategies varied as insight changed with disease progression. Concerns around stigmatisation negatively influenced help-seeking, and acceptance of the hallucinations.

Conclusions

Degree of insight and cognitive ability appear fundamental to the lived experience of hallucinations. Irrespective of the clinical context, support in early stages should focus on

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raising awareness of VH, symptom disclosure, stigma reduction, and contact with others affected. In later stages, the focus shifts to informal caregiver needs and a flexible approach to re-assuring those affected.

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Introduction

Visual hallucinations (VHs) are defined as “experiencing a visual sensory perception in the absence of an external stimulus” (American Psychiatric Association, 2013), i.e. seeing something that others cannot. These can occur in several conditions in old age of which Parkinson’s disease (PD) and the dementias (in particular Alzheimer’s disease [AD], Dementia with Lewy bodies [DLB] and vascular dementia), are among the most common. Prevalence estimates of VHs in these conditions vary widely due to differences in the hallucination type included in studies and recent recognition that prevalence increases with disease duration (ffytche et al, 2017). In early disease stages, VH prevalence estimates range from 12 – 53% in AD, 46 – 65% DLB and 25 – 40% in PD (Chaudhury, 2010).

Considerable research exists on the characteristics of VHs, their etiology and pharmaceutical treatment and the different clinical contexts in which they occur. Risk factors for VHs in both PD and the dementias include longer illness duration, more severe disease, age, greater cognitive impairment, and medication (ffytche et al, 2017). VHs in these conditions have been associated with reduced individual wellbeing, increased caregiver burden, greater functional deterioration, and unfavourable outcomes including increased nursing home admissions, accelerated cognitive decline and mortality (Aarsland et al., 2004; Goetz & Stebbins, 1993; Scarmeas et al., 2005). These outcomes do not seem to be associated with VH in the context of eye disease (Cox and ffytche, 2014). We thus do not fully understand the relationship between VHs and adverse outcomes and whether these could be averted with timely, tailored support. Research on the experiences and needs of those with dementia or PD who experience VHs may help improve our understanding of this relationship. In particular, given clinical overlap between the dementia and PD with parkinsonism characteristic of DLB and progressive cognitive decline and dementia

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occurring in PD, an understanding of how needs and experiences are similar and different in these conditions may help inform the link to adverse outcome.

To date, research addressing this has used questionnaire evidence or caregiver accounts (e.g. Barnes, Connelly, Boubert, & Maravic, 2013; Cohen-Mansfield, Cohen, Golander, & Heinik, 2016). While useful, it is essential to give a voice to the person experiencing VHS to understand the issues involved, as not all individuals share their experiences of VHS with close family (Urwyler et al., 2015) and caregiver and care recipient needs may differ (Lyons, 2002). However it is also vital to understand how VHS impact caregivers and how they can be best supported.

Qualitative studies can examine the VH phenomenon from the individuals' perspective. In this study, we use qualitative methods to better understand the needs, experiences and coping strategies of people with dementia or PD who experience VHS, and the impact on informal caregivers. A related study on the needs and experiences of people with eye disease who experience VH will be reported separately.

Methods

Study design and recruitment

This qualitative study sits within a larger National Institute for Health Research (NIHR) programme (SHAPED – Study of visual HAllucinations in Parkinson's disease, Eye disease and Dementia) which aims to develop clinical management guidelines for individuals with VHS, their carers and healthcare professionals.

SHAPED focusses on routine clinical settings (neurology clinics, ophthalmology clinics, memory clinics, community psychiatric services) and uses the working diagnosis in these clinical settings to define groups rather than research diagnostic criteria. Four clinical groups are identified: eye disease (without dementia), dementia (without eye disease),

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Parkinson's disease and comorbid (eye disease and dementia) using supplementary testing to allocate groups. There are sub-groups within dementia (AD, DLB and mixed dementia [vascular dementia and AD with vascular dementia]) and sub-groups within PD (PD dementia and PD without dementia). All SHAPED participants undergo the same set of assessments to characterise: visual ability (Snellen chart acuity), cognition (a version of the Mini-Mental State Examination modified for SHAPED to accommodate visual impairment [MMSE_{blind}]) and motor function (subset of the Unified Parkinson's Disease Rating Scale [UPDRS]) (see Table 1). These formed part of the context in which the data were interpreted. Participants for the qualitative study were recruited by the first author (SR) from a range of sources to support the transferability of the findings, including Community Mental Health Teams for Older Adults, local memory services, support groups, an online dementia research database, and sites in London and Cambridge participating in SHAPED. Purposive and pragmatic sampling was used to recruit individuals with varying frequency and severity of VHs and living situation, dementia diagnosis and disease stage to encompass a wide range of needs and experiences. Individuals were excluded if they had schizophrenia, epilepsy or narcolepsy.

Potential participants and caregivers were given information sheets and time to ask questions and consider whether they wanted to participate. Some informal caregivers declined on the potential participant's behalf, feeling the interview would be too distressing. Participants with capacity gave informed, written consent to participate. For participants judged to lack capacity, their informal caregiver was asked to act as a personal consultee. The study was approved by the Camden and Islington Research Ethics Committee (Ref 14/LO/1517).

Data collection

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The first author conducted the interviews from October 2015 to March 2016. These occurred at the participants' home in 17 instances. Two interviews were conducted in a care home and two in hospital. Interviews were audio-recorded, transcribed verbatim and anonymised.

Interview schedules were developed based on existing literature and the study objectives. Participants were asked about their experience and interpretation of VHs, the perceived impact of VH experiences on their relationships and daily life and any information or support they had sought and /or received. Informal caregivers were asked to reflect upon participants' and their own reaction to VHs and support received. In-depth interviews allow for rich, open-ended discussion, with flexibility around questioning style, and were amended iteratively to follow participants' concerns (Yardley, 2000). After each interview the interviewer noted key points to explore in subsequent interviews.

Data analysis

Interview transcripts were read repeatedly to enable immersion in the data. Transcripts were analysed using thematic analysis and themes were identified inductively from the data (Braun & Clarke, 2006). Initial codes were managed with NVivo 11 software (QSR International, 2015). Constant comparison technique (Glaser, 1978) was used to capture similarities and discrepancies between participants' responses and develop key themes across the sample.. Informal caregivers were then coded and key themes identified and integrated. Divergent cases with seemingly differing experiences were also sought and examined, which helped add depth to the analysis. A coding scheme was developed based on the emerging themes, which was added to and refined through analysis to ensure they reflected the whole data set. A second researcher (VL) oversaw the coding and theme development and helped identify alternative interpretations of the data. Data collection and analysis ceased when no new themes emerged from the data.

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Results

Ten participants with dementia (PWDs) and ten informal caregivers (ICDs) were interviewed. Confirmation of diagnosis was obtained from the participants' GP or memory service. One further ICD was interviewed who cared for her severely impaired mother for several years before her death. Eleven participants with PD (PWPs) and nine informal caregivers were interviewed (ICPs); two participants lived alone and did not have a relevant informal caregiver. The majority of participants in both groups lived at home with their spouse or family. PWDs generally had been diagnosed more recently and their median MMSE_{blind} score was lower than PWPs. PWPs had a wider range of time since diagnosis and a higher median MMSE_{blind} score.

[Table 1]

Characteristics of VHs

Most participants had been experiencing VHs for at least a year. PWDs were more likely to hallucinate people and animals, whereas PWPs tended to experience people or 'presence' hallucinations, concurring with previous research (ffytche et al, 2017). Some described VHs as occasional, while others experienced them weekly; frequency was unpredictable and most could not identify a trigger. Several participants, mainly PWDs but some PWPs, also experienced auditory hallucinations and delusions. Many participants and caregivers welcomed the opportunity to discuss their VH experiences, though for many the interviews focused on the wider effects of PD or dementia, such as reduced independence, memory problems, or frustrating physical symptoms. VHs appeared part of a complex disease picture, often considered a 'nuisance', but rarely the most concerning aspect.

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Findings are presented across participant groups as three overarching themes: ‘Insight and distress’, ‘Caregiver approach: challenging v reassurance’, and ‘Normality and stigma’. Similarities and differences between participants are highlighted where relevant.

Insight and distress

[Box 1]

The theme of insight was prominent in these interviews. Overall, it appeared that the more insight participants had into their VHs (i.e. recognising them as a symptom of their condition), the less threat they posed, and they were more able to accept them as part of their life. As participants’ insight declined and their recognition of reality became unclear, VHs were more likely to provoke fear and were thus less easily accepted as part of life.

Intact insight. For PWP with relatively preserved cognition, many reported a phase of uncertainty and distress when VHs first occurred (Box 1, 1a). However they became less concerned over time as they learned the VHs were not real. For some, this realisation came through discussing the experience with their informal caregiver and with continued exposure they realised the VHs did not respond or harm them (Box 1, 1b). Gradually they saw the VHs as less threatening and simply another symptom to contend with, thus enabling them to accept VHs as part of their life (Box 1, 1c). Few of these participants reported concern about how VHs may affect them in the future. Informal caregivers also tended to accept the VHs as part of their lives if they did not cause the participant distress (Box 1, 1d).

Declining insight. More cognitively impaired participants (PWD and PWP in more advanced stages) were often uncertain about reality and less likely to recognise VHs as a symptom of their condition i.e. they felt they were real.. Consequently, they were more likely to feel threatened by the VHs (Box 1, 1e). The interviewer had to exercise sensitivity, as participants believed VHs were real and were uncomfortable with suggestions to the

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contrary. However this did not necessarily mean they did not accept them as part of their life (Box 1, 1g). Acceptance occurred if the content of the VH did not cause distress or, if the VH did provoke distress, this was subsequently ameliorated through caregiver reassurance or though attending to the dilemma posed by the VH.

Some cognitively impaired participants were dismissive of their quality of life being affected by VHs, which often conflicted with the perspective of their informal caregivers (Box 1, 1h, 1i).

Caregiver approach: challenging v reassurance

[Box 2]

Informal caregivers' reactions were closely related to participants' perceived insight. When they felt the participant knew the VHs were not real, they would usually offer simple reassurance e.g. acknowledging they had seen something or saying it could not hurt them. Several said they would often laugh with the participant and make a joke out of the situation. One PWD and ICD dyad named his VH of a shadowy man, which helped them to accept that he was not a threat.

As participants became more cognitively impaired and begun to lose insight, managing the VHs appeared to become more challenging for informal caregivers. Many were unsure how to react or whether their reaction was 'right' (Box 2, 2a, 2b). Some informal caregivers of participants who were mildly cognitively impaired (late stage PWDs and early stage PWDs) aimed to orientate them to reality by challenging their belief that the VHs were real (Box 2, 2c). Some would challenge the content of VH by physically exploring the environment (Box 2, 2d). Those with less insight were often angry or upset at being told the VH was not real (Box 2, 2e).

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Other informal caregivers, mainly those supporting a PWD with severe cognitive impairment who lacked insight into their VHs, said they regularly “colluded” with the VH to try to reassure the participant. In this context reassurance often focused on solving the problem posed by the VH or attempting to downplay the threat. Some were uncomfortable with this, however, as they felt they were deceiving the participant. As participants declined, informal caregivers had to find more elaborate reassurance methods to reflect this change in insight (Box 2, 2f, 2g). If the VH was pleasant, informal caregivers felt more comfortable going along with the participant. However if participants were distressed, informal caregivers tended to acknowledge the experience as real and acted to remove the threat, but this was not always easy (Box 2, 2h).

Informal caregivers’ quality of life sometimes appeared more adversely affected by the VHs than participants’. This occurred in instances where caregivers felt they could no longer leave the participant alone in case they reacted negatively to the VHs, or because of interrupted sleep (Box 2, 2i). Informal caregivers for both conditions were more likely to express concerns about the future than the individual themselves, such as the VHs becoming more distressing and not being able to cope with them (Box 2, 2j). Some informal caregivers had considered moving the participant into a care home, although they were reluctant as they felt it would be against the participant’s wishes, and they wished to keep them at home for as long as possible. This was rarely directly attributed to VHs and could reflect informal caregivers struggling to cope with severe physical and cognitive impairment. A small proportion of severely impaired PWDs had moved into a care home partly due to the VHs (Box 2, 2k). Many coped by dealing with things one day at a time (Box 2, 2l).

Normality and stigma

[Box 3]

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Some informal caregivers, mainly those supporting a participant with insight into their VHs, discussed ideas around what was ‘normal’ and the stigma associated with VHs, occasionally using language like ‘strange’ or ‘weird’ to describe the phenomenon. This was mentioned by some PWDs, but mainly by PWP who felt that experiencing VHs was ‘crazy’ and ‘not normal’, and that others, such as family or health professionals, were unlikely to believe them (Box 3, 3a, 3b). A few participants, mainly PWP, described feeling embarrassed or ashamed (Box 3, 3c).

Around a third of the PWP had not heard of anyone with PD experiencing VHs and were reassured that others also experienced them (Box 3, 3d). Similarly, a few informal caregivers of PWP wondered whether they were alone in dealing with VHs. Feeling ‘abnormal’ appeared to prevent participants from discussing and seeking support for VHs, although others said they did not feel they were important, or that discussing them would achieve anything. However the majority of participants for both conditions had told their informal caregiver about their VHs, and some informal caregivers reported sharing this information with other family members and friends. Reasons for discussing VHs included finding out they were not alone and not having to cope by themselves (Box 3, 3e, 3f). Some informal caregivers explained that having supportive others around who understood the situation could help to normalise the experience (Box 3, 3g).

Discussion

This is the first qualitative study to compare the needs and experiences of people with dementia and those with PD who experience VHs, and their informal caregivers. For the majority of participants in our study, VHs were not the most concerning aspect of their condition, with many mourning their loss of independence or other physical (e.g. pain,

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limited mobility) or psychological (e.g. memory, depression) issues. However some participants, especially those with greater cognitive impairment, were more distressed by their VHs. Despite differences in clinical presentation, with predominantly motor symptoms in PD and predominantly cognitive symptoms in dementia, and differences in the type of hallucination experienced (e.g. presence hallucinations in PD), we found a greater similarity than difference between the lived experience of VH in the two groups. Participants and carers from PD and dementia contributed to each theme, with no suggestion for any theme that it was specific to one or other condition. Overall, our findings suggest the degree of insight and cognitive impairment is more influential in determining the needs and experiences for individuals with VHs than a clinical diagnosis of PD or dementia.

Individuals with dementia and PD who had insight into their VHs initially found them distressing, but with repeated exposure realised they were not threatening. This acceptance sometimes came through talking with their informal caregiver, but mainly through self-learning. This is consistent with a previous qualitative study of older adults with dementia and visual impairment (Lawrence, Murray, ffytche, & Banerjee, 2009) where participants with insight into their VHs said discussing them helped with the ongoing challenge of separating their experiences from reality, aiding understanding and acceptance and thereby lessening distress. In contrast, for individuals lacking insight, VHs could be highly distressing for both the individual and caregivers.

Caregiver distress appeared to increase as participants' cognition declined, concurring with existing literature (Khoo, Chen, Ang, & Yap, 2013). VHs can cause significant caregiver distress (Matsumoto et al., 2007; Morandi et al., 2015), especially if they are uncertain how to respond; many dementia caregivers feel they lack information about managing behavioural and psychological symptoms (McCabe, You, & Tatangelo, 2016), and PD carers report a lack of tangible, practical solutions to VHs (Lawson, 2015). In our study, VHs were initially

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unsettling for caregivers. Many were unsure if they were responding ‘correctly’, and this could negatively impact the caring relationship. The content of the hallucination, whether neutral or threatening, also influenced the informal caregiver response. Several informal caregivers appeared to adapt their management strategies over time as insight declined, consistent with previous studies with people with dementia (Lawrence et al., 2009) and PD (Williamson, Simpson, & Murray, 2008), where an initial inclination to challenge the individual shifted towards comfort and reassurance to reduce distress. As VHs can precipitate a move from independent living to care (Goetz & Stebbins, 1993), as was evident in our study, managing individual and caregiver distress could be vital to delay this. Our findings emphasise the importance of understanding individuals’ degree of insight into VHs as it affects how both they and their caregivers respond.

Although early support could be important for alleviating initial distress, individuals experiencing VHs may feel embarrassed about disclosing this to health professionals (Schofield, 1997; Gupta, Singh, Khwaja, & Mehndiratta, 2004), a reflection of the perceived stigma of experiencing VHs. A reluctance to disclose VH also occurs because of a perceived link to dementia (Cox & ffytche, 2014). This did not seem to occur in our study, as even people who recognised they had dementia could feel ashamed of their VH experiences, perhaps because they were not aware of the link. Such stigma will prevent people from seeking support for VHs and prevents wider understanding, which could contribute to distress. Raising awareness about VHs could reduce feelings of shame and reluctance to seek advice. Health professionals should enquire about VHs to shift the onus of disclosure from the individual or their caregiver, and should be educated about VHs to reduce stigma and ensure they feel knowledgeable about VH management (Rüsch, Angermeyer, & Corrigan, 2005).

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Overall our findings suggest that support for VHs in both PD and dementia needs to be individualised, considering several factors including the degree of insight and cognitive function, type of hallucination and personal circumstances of the person experiencing them. In early stages of the conditions, when insight and cognitive function are still preserved, both the person experiencing VHs and caregivers would benefit from support focusing on raising awareness of VHs and treatment options, providing opportunities for symptom disclosure, reducing stigma, and contact with others affected. Acknowledging VHs and reassuring that they are not harmful appears sufficient at this stage. As the conditions progress and insight and wider cognitive function become impaired, the focus of support shifts to caregiver needs and alternative strategies to reassure individuals experiencing VHs. This might include recognition that a VH is the individual's reality at the time. Attempts to solve problems posed by VH may be more appropriate than challenging their existence at this stage.

A major strength of this study was that individuals' first-hand accounts were triangulated with those of their informal caregiver, allowing needs and experiences of both to be considered. There was a wide range in participants' MMSE_{blind} scores and time since diagnosis, capturing experiences across the disease spectrum. The majority had been experiencing VHs for at least a year, and many appeared to have accepted their VHs or no longer found them distressing; further research could focus on individuals who have recently begun experiencing VHs, as they may report more distress and uncertainty. Additionally, highly distressed individuals may have been less likely to participate; indeed some informal caregivers declined participation citing this reason. While there was an even split of male and female participants in the dementia cohort, there was a lack of male informal caregivers, with no husbands or sons being interviewed. This may reflect women being more likely to be caregivers than men (Pinquart & Sörenson, 2006). There were more participants with DLB than AD or vascular / mixed dementia in the dementia group, reflecting the higher prevalence

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of VHS in DLB (Fénelon & Mahieux, 2004). It is therefore possible the findings might have been different if the group was predominantly AD. However, given that one might expect the experiences of different sub-types of dementia to be more similar than dementia and PD, this seems unlikely in the overall context of our findings. Finally, insight in this study is based on the global impression given by participant and carer interviews rather than measured by a specific questionnaire. It would be informative in future studies to have a quantitative measure of insight to better explore its impact on the lived experience of VH.

Conclusion

This study provides a rich insight into the VH experience of both individuals with dementia and those with PD and their informal caregivers, which has not previously been explored concurrently. The differences in the VH experience between persons with dementia and those with PD such as type of hallucination (presence versus formed) were less striking than the overall similarities across conditions at equivalent stages of cognitive and insight impairment.

Instead of being treated as distinct conditions, clinical management guidelines for VHS should focus on support according to the level of insight and cognitive impairment. Health professionals, from doctors and nurses to formal carers, should receive training regarding the management of VHS to aid affected individuals and their informal caregivers. This information provision should occur soon after diagnosis to prevent stigmatisation and distress and foster acceptance. There should be continued support and adaptation of carer management strategies as the individuals' cognition and insight declines.

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Table 1 Participant characteristics

	Dementia (n=10)	Parkinson's (n=11)
Gender: female/male	6/5 ^a	7/4
Age		
Mean (range)	79 ^a (66-89)	75 (66-86)
Ethnicity		
White	9 ^a	10
Black	1	0
Mixed	1	1
Condition		
Lewy Body dementia	6 ^a	-
Mixed dementia	3	-
Vascular dementia	1	-
Alzheimer's disease	1	-
Idiopathic Parkinson's disease	-	10
Parkinson's disease dementia	-	1
Time since diagnosis		
Mean (years)	2.6	11.4
Median (years)	3	9.25
Range	2 months – 5 years	1 year – 30 years
Living situation		
Living with spouse	5	8
Living with family	3	0
Living in a care home	2	1
Living alone	1	2
Informal caregiver		
Wife	5	4
Husband	0	4
Daughter	5 ^a	1
Daughter-in-law	1	0
No study partner	0	2
MMSE _{blind}		
Mean	16/28	24/28

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Median	17.5/28	26/28
Range	10 – 21	14 – 28
10 – 15	3	1
16 – 20	4	1
21 – 25	1	3
25+	0	6
Not completed	2	0
UPDRS		
Mean	3.25/20	7.3/20
Range	0 – 7	2 – 16
Not completed	2	0
Snellen Acuity ^b		
6/12 or better	3	6
6/18 or worse	4	5

^a Includes participant characteristics for one deceased participant whose informal caregiver was interviewed. ^b Corrected acuity best eye. Three dementia patients were unable to complete acuity tests.

Box 1: Direct quotes from study participants relating to the theme, ‘Insight and distress’

Intact insight

Initial distress

1a) I could see figures standing over me and then all of a sudden they’d come closer and closer, they didn’t really have a face but it just frightened you because it was all black. And then I felt them crawling up the bed and it’s terrible, you’re awake and you’re in a nightmare with it and it was horrible. (PWP6)

Dissipating threat

1b) At the beginning perhaps it disturbed me more, now I know it’s not a threat of any sort that nothing’s gonna harm me or hurt me and it’s just like go away you’re a nuisance. (PWP5)

Living with VHs

1c) I know it’s part of my condition so I try to get on with it. Otherwise I’ll make myself depressed and I don’t want that. (PWP1)

1d) There’s nothing they can do about it. And so long as it’s not distressing, well (laughs) let him keep seeing people it’s ok, he’s quite happy with it, if it doesn’t bother him then leave him be. (ICD1)

Declining insight

VHs as frightening reality

1e) I was confused because I thought I was lost in Singapore, I said how will I come back, so they took care of me for a while, and eventually everything disappeared but in the moment it was quite staggering. And that’s very, very surprising. (PWD1)

Accepting unthreatening VH

1g) The last house before the new one, there’s erm a couple of boys, or might be a bit more than that, yes and they come in, they like the garden really. (PWD6)

Negative impact of VH on quality of life

1h) Mum’s actually awake a lot of the night looking for the tigers, looking for the children, coming up the nurse’s station, she’s up all night and that’s why she sleeps a lot during the day. (ICD5)

1i) We get a bit frustrated you know with the imaginary people who are ruling her life (laughs) so that she can’t do her normal activities ‘cause she’s waiting for them to come in or got to go back and let them in and things like that. (ICD6)

Box 2: Direct quotes from study participants relating to the theme, “Caregiver approach: challenging v reassurance”

Uncertainty surrounding caregiver approach

2a) To be quite honest I didn’t know what to do about it, I didn’t know whether I was supposed to agree that what he was seeing was right, whether I was supposed to say oh there’s nothing there, or whether to make a joke of it even. (ICD9)

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2b) I don't know really what I would do. I would probably just sit her down and talk to her and you know reassure her there's no one here, but I don't really know if there's a right way of saying something or a wrong way of saying something. I mean perhaps I should have some lessons (laughs). (ICP4)

Challenging belief VH is real

2c) I just turn round and say [participant], it's all a load of crap to be honest with you, that's what I say (laughs). And I say to her, [participant], it's not real. (ICP1)

Refuting content of the VH

2d) Sometimes I would take him to the settee and say look there's nobody here, sometimes he said they were in the bathroom so we went to the bathroom but there wasn't anybody there. That was how I dealt with it best. (ICP9)

Anger at being challenged

2e) I always have a go at my son, I did see someone there you know, I'm not deaf I'm not blind I do see things (laughs) but I don't want to get in another argument...I just sit in my chair and have my mood. (PWD10)

Downplaying the threat

2f) We had a bison that tried to get through our cat flap and she'd go "[name] get in here", so I went in the back room and she said "oh look that bison, get it out it's gonna break our cat flap!" ... So I got hold of the bison and I'm leading it outside, I got down the hall to show it out of the kitchen door. (ICD0)

2g) If she says "well [daughter's] children were here and they've run off and they haven't come back", then I can phone my sister and say "are the children alright are they home in bed", and she says "oh yes they are", I'll tell mum, "mum the children are home in bed", "oh that is a relief to me", she'll say. (ICD6)

Challenge of removing threat

2h) Well they do say you should go along with these things, and if we all have to sing Land of Hope and Glory at the tops of our voices to avoid some crisis, yes you go along with it. But how do you go along with babies being thrown into bonfires? You can't say oh yes there are babies being thrown into bonfires. (ICD0)

Adverse impact on caregivers' quality of life

2i) He started to get violent with it, verbally abusive every night and every morning, I just didn't know what I was gonna get up to, I used to come down in the morning and before I got down I'd be accused of horrendous things all through the night that I'd done. And I wasn't getting any sleep. (ICP11)

Caregivers' concerns about the future

2j) It makes things more complicated. And it means that if the hallucinations get more frequent or upsetting, then I'm not quite sure what the next step would be, it's something we'd have to think about. (ICD1)

VHs as contributing factor to care home admission

2k) She's been here for about a year and a half now, prior to that we were trying to keep her at home but it was unsustainable, the relationship with her husband wasn't so great and also the hallucinations were getting worse and worse...it all just got really out of hand and medication

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wasn't being taken properly, so that's when [social worker] got involved and eventually it's ended up with her coming here. (ICD5)

Managing “day by day”

2l) I'm not worried about it, I mean we'll deal with it for as long as we can. And if me mam's gonna need more help than what we can give her then we'll cross that bridge when we come to it but at the moment we'll just go from there. (ICD10)

Box 3: Direct quotes from study participants relating to the theme, “Normality and stigma”

Stigma and reluctance to disclose

3a) 'Cause nobody's going to believe it are they? ... Let's ask a silly question, how many people are going to say they're seeing something? They're not really are they? (PWD8)

3b) Well you think, if you tell someone that you don't know, you think they think you're crazy, that's why I don't want, you know the people that's outside, I don't want anybody to notice it, that there's a mad lady outside there, no I don't like, I don't do it, I just keep it. (PWD10)

VHs as “madness”

3c) I was embarrassed 'cause you see people in [home country], for them somebody being that is crazy, if you're behaving like that you see water the place flooding and there's nothing it's dry, they say she's crazy or she's mad or something like that. (PWP10)

Value of discussing VHs

3d) I was so pleasantly surprised that there was somebody who had experienced this. And I thought oh it's not obscure, I'm not in trouble, I'm not the only one that's had it...other poor souls have it as well (laughs). (PWP3)

3e) Some people, they're not keen to put it out there, they won't say nothing about it, but I'd rather say and get it there and done by sort of thing. (PWD9)

3f) You know you're not alone, you've got other people you know the same thing like yourself, and you say well I know I'm not alone so you feel a lot better. (ICD3)

3g) I go to the gym and there's a group of ladies there, one of the ladies that I talk to a lot her sister had Lewy Body dementia, and they all know [participant] 'cause he used to come to the gym with me, and so you know they're people I can talk to about it and they'll say oh how's things. (ICD7)